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AN EXAMINATION OF THE CONCERNS OF PARENTS WHO HAVE HAD
A CHILD IN A PEDIATRIC INTENSIVE CARE UNIT

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Presented for the
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Degree
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ABSTRACT

The entire family is affected by a child's admission to a Pediatric Intensive Care Unit (PICU). Problems may result from physiological, psychological, sociocultural, developmental, and spiritual stressors. Parents may need support and assistance, before they can support their child.

The purpose of this study was to examine the concerns of parents and the methods they use to respond to those concerns. Neuman's Systems Model provided the theoretical framework. Subjects included parents of children who were admitted to the PICU for the first time, then discharged to the General Pediatric Floor. A qualitative, descriptive method was used. Answers to a demographic questionnaire and a structured interview were compiled and examined for recurring themes and categories. Themes were analyzed for frequency, importance, and meaning.

Major findings indicate that parents who have a child in a PICU are concerned that the child may die or have lasting defects, the entire environment is frightening, and explanations from care providers are frequently not understood. Parents respond to concerns by relying on faith in God, talking to others, physical activity, crying, and intellectualization. Serendipitous findings include a preference for structured, set visiting times. Parents also

expressed distress when the nurse was responsible for enforcing the parent lounge rules.

The child is part of a whole family system. In order to effectively treat the child, the parents must also be treated. By identifying the concerns of parents, effective, purposeful nursing interventions may be developed to reduce the detrimental impact of stressors upon the family system.

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CHAPTER I

THE RESEARCH PROBLEM

INTRODUCTION

A Pediatric Intensive Care Unit (PICU) is a unit specifically designed to care for critically ill or injured infants and children. Admission to the PICU occurs for a variety of medical and surgical reasons. Common admission diagnoses include: trauma (motor vehicle accidents, falls, burns, gunshot wounds, near-drownings, child abuse, and suicide attempts); respiratory emergencies (epiglottitis, severe croup, bronchiolitis, asthma, pneumonia, and pneumothorax); post-operative care (open-heart surgery, abdominal surgery, and orthopedic surgery); and neurological emergencies (spinal cord injuries, seizures, meningitis, and shunt malfunctions). Children in the PICU receive continuous treatments and monitoring by a team that consists of physicians, nurses, respiratory therapists, dietitians, physical therapists, social workers, child life workers, and chaplains. The focus of the staff's efforts is directed towards saving the child's life and restoring as much function and ability as possible.

The PICU can be a great source of stress for the parents. In a PICU, the child is surrounded by a vast array of unfamiliar equipment with flashing lights, moving parts, and numerous alarms. The alarms often sound when the parents are at the bedside. The child's appearance may also be frightening to the parents. The child often has intravenous lines, endotracheal tubes, monitoring lines, chest tubes, bandages, and urinary catheters. The use of all the monitors and tubes sometimes restricts the child's movement or ability to get out of bed.

The entire family is affected by a child's serious condition and admission to a PICU. Emotional, intellectual, financial, spiritual, and social stressors impact upon the family. A stressor may be defined as anything which causes a decrease in the level of functioning or state of health of an individual or family and results in problems or concerns. Stressors may be brief or extended over weeks, months, or even years. Communication is rarely ideal between nurses and parents of infants and children in a PICU due to the critical nature of the child's illness or injury, the parent's level of stress, and the nurse's focus upon saving the child's life.

The normal routine of family life cannot be maintained when a child is in a PICU. Stressors affect the entire family. Parents often must take time off from their jobs.

Some use their sick time, vacation time, or take a leave of absence. A parent may even lose their job if time off is not allowed. This can have severe effects upon a family because there may not be enough money for rent, food, or hospital expenses. It is very difficult for parents to take care of their child's needs when they are in need of assistance themselves.

Parents may be defined as biological or adoptive mothers, fathers, mother-father pairs, primary caretakers, or guardians of infants and children. Under most circumstances, parents are very protective of their children. The researcher has noted, however, that when a child is in a PICU, most parents do not complain, even if they are fearful for their child's safety. Parents may become very upset or angry at the actions of the staff or about a certain treatment administered to their child, but they usually fail to share their thoughts and concerns with the unit nurses, physicians, or supervisors. They may be afraid to share their concerns because they fear retaliation from the staff.

The parents often become upset due to a misunderstanding rather than a true problem. The explanations given by the care providers may not be clear to the parents and they may be afraid to ask too many questions. Their unwillingness to share their concerns can

result in feelings of helplessness, loneliness, hostility, and a lower regard for the staff and the institution.

Nurses in the PICU have noted that parents are often reluctant to admit that they do not understand what is happening or to ask too many questions concerning the care of their child. Although there is no documentation of these phenomena, the researcher has often observed parents appearing to be listening attentively and nodding their heads while a physician speaks with a strong foreign accent or uses a lot of confusing medical terms. These same parents, when questioned, will admit that they did not understand anything the physician said.

It is important for nurses to be aware of the concerns of parents in order to address those concerns and to offer information needed to understand the situation in realistic terms. Parents often have misconceptions about their child's treatment and care. If they share their ideas and feelings with the staff, misconceptions can be detected and the correct information can be given.

Children in the PICU need the support of their parents in order to obtain optimal recovery. The parents need to be supported and assisted so they can give support to their child. By airing the parent's concerns, the staff can offer information, give guidance in making decisions, and lend support. If the parents are assisted in managing this new

and difficult experience, they may be more effective in supporting their child.

PURPOSE OF THE STUDY

The purpose of this study was to examine the concerns of parents who have had an infant or a child in a PICU and to explore the methods parents use to respond to those concerns about their child's treatment and care.

SIGNIFICANCE OF THE STUDY

The results of the study may be used to identify ways to improve communication and understanding between the parents and the nursing staff and to develop educational programs for PICU nurses dealing with specific methods to enhance communication with parents. Such actions are expected to promote bilateral understanding of the situation, to decrease the parents' level of stress, and to prevent future communication problems. If the parent's needs are met, they are more able to assist their child in recovering from a critical illness or injury. Thus, helping the parents helps the child.

CHAPTER II

LITERATURE REVIEW

INTRODUCTION

In this chapter, literature concerning the parents of hospitalized children is examined. In order to effectively treat the child, the parents must also be considered. The parents' needs, the stressors that affect them, their emotions, and their concerns will be addressed.

NEEDS OF FAMILIES WITH MEMBERS IN CRITICAL CARE

Having a child admitted to a Pediatric Intensive Care Unit is not a common experience for most families. It is usually an extremely emotional and stressful event. Even the strongest families may need assistance in order to cope with the ordeal. The parents can be helped by friends, family, clergy, social workers, physicians, and nurses.

The needs of parents of hospitalized children were explored by Terry (1987) who found the necessity of obtaining information was the parents' greatest need. The parents were asked to rank 44 need statements on a Likert scale. Parents identified physicians and nurses as the

people who could meet most of their needs. The physician was viewed as the person who could provide informational needs and the nurse as the person who could provide for ventilation and support needs. A limitation of this study is that only two open ended questions were asked; one concerning the parent's greatest need and the other concerning the person most likely to meet that need. Unfortunately, this approach limited the parent's responses to the ideas of the researcher.

Daley (1984) examined the needs of families of adult patients in an intensive care unit setting and found that they perceived the majority of their needs to have been met by the physician. These findings may be related to the fact that families were asked to rank their needs within the first 72 hours of admission. Their needs may change as the time spent in the intensive care unit increases. A previous study by Molter (1979) identified that the majority of family needs of adult patients were met by nurses. This study did not specify a set time frame for collection of information.

Kasper and Nyamathi (1988) examined parental role needs identified by both mothers and fathers while their child was in a PICU. They divided parental needs into categories and subcategories. The parents expressed the greatest majority of their needs as psychological, with physiological needs

second, and sociological needs third. Their most important needs were identified as being with the child in the PICU and receiving frequent, honest information about their child's condition.

Parents need to visit their child while in the PICU. Most nurses and doctors who work in a PICU believe that parental visitation should be liberal, individualized, and unstructured. A study by Proctor (1987) found that mothers had lower state anxiety scores if the PICU visitation was individualized rather than highly structured. Stillwell (1984) studied the perceptions of visiting needs by family members of adult intensive care patients and found that they identified the need to see the patient frequently and whenever they desired to be of greatest importance to them. Their visiting needs were ranked within the first 36 hours of admission. The conclusion drawn was that the visiting times in the ICU should not be restricted so that the family members of the adult patients would have visiting flexibility. The findings of this study may have changed after the first 36 hours of admission.

Prior PICU experience can influence the ways in which parents voice concerns to get needs met by care providers. Wyckoff and Erickson (1987) suggested that if parents have had past experiences in caring for a critically ill child, they will show an improved ability to manage the situation.

Familiarity may increase the parent's coping skills. Tse, Perez-Woods, and Opie (1987) examined parental attitudes and outcome expectations when their children were admitted to the PICU. They determined that parents with previous experience or knowledge of similar situations had higher positive expectations for their child to recover and for a favorable outcome.

STRESSORS

The parents of a child in a PICU face numerous stressors. Miles (1979) identified these stressors as coming from three main areas: (a) the fear of the child's illness or injury outcome, (b) the anxiety of dealing with a different environment, and (c) the loss of the parental role. Parental stressors can affect the parents' ability to handle the crisis because they may be unable to provide emotional support for their child when they receive no emotional support for themselves. The child in the PICU requires the presence and support of his/her parents. If the parents are unable to provide support, the child suffers even more. Therefore, in order to fully care for the child, the parents must also be cared for.

A study done by Tichy, Braam, Meyer, and Tattan (1988) examined PICU stressors from the child's point of view.

They identified parental expressions of anxiety as a source of stress for the child in the PICU. None of the parents in the study were aware that their anxiety increased their child's level of stress.

Miles, Carter, Spicher, and Hassanein (1984) studied maternal and paternal stress responses in a PICU and found that the total experience is equally stressful for both parents. Alterations in the parent-child relationship were more stressful for the mothers than the fathers, whereas a sense of helplessness, a whining or unresponsive child, and visitation restrictions stressed the fathers more than the mothers.

PARENTS' EMOTIONS

Only a few researchers have examined parent's emotions when they have a child in a PICU. Rothstein (1980) found that parents undergo feelings of shock, disbelief, and helplessness when their child is admitted to a PICU. These emotions may last for hours or days. They are the result of the suddenness of admission and the unusual appearance of the child created by the tubes, bandages, machines, and manifestations of the injury or illness. The parents become anxious as they search for a reason or meaning for their child's condition. They may blame themselves or others.

These findings are consistent with a study done by Daley (1984) demonstrating that families experience both anxiety and disorganization after a family member's admission to a coronary care setting.

When the parents move from the stage of disbelief and helplessness, they start waiting for the recovery of their child with anticipation (Rothstein, 1990). Anger may be expressed during this period. Parents may take their anger out on family members or the staff, especially if the waiting stage is prolonged. Some parents may be fearful of losing control of their emotions. Rothstein (1980) states that the last parental responses are elation and mourning. Although they may be happy that their child has made enough progress to leave the PICU, the prospect of a long recovery may lead to mourning of the loss of accustomed family life, freedom, and financial stability. The parents may be anxious about leaving the familiar staff and moving to the General Pediatric Floor where there is a lesser amount of attention given to the large number of children.

CONCERNS OF THE PARENTS

No specific research studies have been done to explore the precise concerns of parents who have had a child in a PICU. Their physiological, psychological, and sociological

needs have been looked at by a few researchers, but not their specific concerns about their child's treatment and care while in a PICU.

CHAPTER III

THEORETICAL FRAME OF REFERENCE

INTRODUCTION

The theoretical framework for this study was provided by Neuman's Systems Model. This chapter will discuss the application of this nursing model to the concerns of parents who have had a child in a Pediatric Intensive Care Unit.

THE SYSTEMS MODEL

The systems concept involves the relationship between the whole and its parts. Within the parts of any system are subparts and elements. If something affects a part or a subpart, there is a resulting effect upon the entire system. Events do not occur in isolation, but result in an effect upon the interrelated parts of the whole system. The child who is admitted to the PICU is a part of a whole family system. In order to treat the child, the whole family must be considered.

This framework was applied to the parents of children in the PICU. Children are complex systems within even more complex family systems. Anything which affects a part of

the child results in a effect upon the whole family system. The parents are affected by the child's serious illness or injury and admission to the PICU.

The extent to which the parents are affected by the child's serious condition depends upon the interrelationship of certain individual variables. The resulting effects upon the parents and their subsequent concerns about the child's outcome depends upon the parent's own unique psychological, physiological, sociocultural, developmental, and spiritual variables.

The parent may have been driving the car when a wreck occurred. Psychologically, the parent may feel very guilty, even if he/she did not cause the accident. Physiologically, the parents may be exhausted due to a lack of sleep. They may be hungry because they have forgotten to eat regularly or do not have the financial resources to buy hospital food. Socioculturally, the parents may be affected if they are worried about paying the hospital bill without health insurance. Some of the parents of children in the PICU are actually children themselves. Fourteen and fifteen year old parents may not be allowed to progress developmentally through adolescence to young adulthood when their child is seriously ill. The spiritual needs of the parents must be considered when they have a child in the PICU. They may need to talk to the hospital chaplain or their own spiritual leader.

Neuman (1982) describes human beings as trying to maintain health within the system by adequately coping with external stimuli called stressors. The stressors can be harmful or beneficial. Harmful stressors may cause a decrease in the level of functioning or state of health of the individual while beneficial stressors may encourage some risk taking that results in an improved state of health or well-being.

The parents of infants and children in the PICU are affected by numerous stressors, most of them harmful. These stressors may be classified as intrapersonal (within the individual), interpersonal (between the individual and others), or extrapersonal (outside the individual). An example of an intrapersonal stressor for a parent who has a child in a PICU would be the physical pain felt as a result of also being injured in the motor vehicle accident that caused the child's injuries. Interpersonal stressors would include the parent's separation from their other children or anger and blame placing within the family while they are waiting at the hospital. Financial stress due to the child's hospitalization falls into the category of an extrapersonal stressor.

According to Neuman (1982), the degree to which the individual responds to a stressor depends upon the individual's normal line of defense, the length of time over

which the stressor occurs, and the interrelationship of the individuals own five variables which make the person unique (physiological, psychological, sociocultural, developmental, and spiritual). The normal line of defense involves the wide range of physiological and psychological responses the person has acquired during their lifetime. These vary with each individual and depend upon the person's physical state of health, developmental stage, coping mechanisms, and past life experiences.

The normal line of defense encircles and protects the individual from the impact of stressors. There is another protective ring, which surrounds the normal line of defense, called the flexible line of defense. This outer ring is dynamic and protective according to Neuman (1982). The parent's ability to use the protection of this flexible, defensive line depends upon the interrelationship of the previously identified five variables (physiological, psychological, sociocultural, developmental, and spiritual).

After exposure and reaction to a stressor, reconstitution may occur. This involves the return of the individual or family to adequate functioning. The parent may achieve reconstitution at any stage in a child's illness. It may occur during hospitalization or after discharge. Reconstitution can result without the child achieving total physical and mental health. It is described

by Neuman (1982) as adaptation to stressors. Therefore, the parent may reconstitute and adapt to a child's long-term illness or lasting defects.

The concerns of parents who have a child in a PICU may be due to the effect of the stressors upon the whole family system. Stressful events cause concerns. The stressors and concerns are often identified in order to develop effective, purposeful nursing interventions. These interventions are aimed at reducing the detrimental impact of stressors upon the family system. If the nurse can assist the family in coping with their stressors and adjusting to the child's illness or injury outcome, then reconstitution may occur.

Neuman (1982) states that the goal of nursing is to assist patients and their families to achieve wellness through purposeful nursing interventions aimed at reducing stress and adverse conditions. Purposeful nursing interventions may be accomplished through primary, secondary, or tertiary modes of prevention. These prevention modes can be used separately or together. Primary prevention involves identification and adjustment of risk factors. Secondary prevention relates to the actual diagnosis and treatment of an illness or an injury. Tertiary prevention describes the adaptive phase where reconstitution occurs. The PICU nurse purposefully intervenes to assist the parent, using each of these three

modes. An example of primary prevention would be the identification of the parent's specific concerns and stressors. Secondary prevention would involve addressing the issues which concern the parents. Tertiary prevention could involve assisting the parents to understand and cope with their child's long-term developmental delays and physical limitations.

Neuman's (1982) Systems Model is a very comprehensive, holistic approach to the care of patients and their families. This theoretical framework was used as a basis for the development of this study. The critical aspect of the theory is that not only the PICU patient's concerns, but also that the parent's concerns, must be considered in planning and implementing nursing interventions. The patient is not viewed in isolation, rather as part of a whole family system. The child's illness or injury and admission to a PICU has a profound effect upon the entire family. The nursing process should address the concerns of the entire family system. Everyone and everything that affects the child must be considered.

The nursing process of assessment, goal setting, identification of nursing outcomes, evaluation, and further assessment and goal setting continues in a circular manner. The nurse works with the child and the family system to assess, to intervene using the three prevention modes, and

to evaluate nursing outcomes. By following this holistic, systems approach, nurses can help children, in the PICU, and their parents to achieve wellness through identifying and addressing their concerns and attempting to alleviate their stressors. The child and the family in a PICU would benefit from the systems approach.

CHAPTER IV

METHOD AND PROCEDURE

DESIGN

This study involved a qualitative research approach. This open, non-experimental design was chosen in order to allow unrestricted, in-depth exploration of the concerns parents experience when they have a child in a PICU. A qualitative design enabled the study to follow a more holistic framework. The whole phenomenon of having a child in a PICU was examined with a focus upon the concerns of the parents. According to Rogers (1987), a study of parents in the PICU is very difficult due in part to the drama of the situation into which they have been thrust, often without warning or preparation.

SETTING

The setting for the study was a 602 bed university affiliated medical center located in the southeastern United States. The PICU is an eight bed unit that includes medical and surgical patients with a variety of diagnoses. Children range in age from newborn to approximately fifteen years.

The PICU has a usual occupancy rate of 80 to 100%. Six of the beds are in an open room. There is a dividing wall in the middle of the room which limits visibility within the room. One can usually only see the activity involving three patients at a time. There are two private rooms in the PICU. One is located inside the PICU while the other is located right outside the unit's main entrance. There are windows in the private rooms which connect with the main PICU. Each private room is equipped with audio and video monitors that are viewed from the nurses' station, inside the PICU. The private rooms are usually reserved for patients requiring isolation, patients who have shown improvement in their condition and require less intense nursing care, or those patients who require less light and noise stimuli for recovery.

Nursing care is provided by an all Registered Nurse (RN) staff, usually on a one to two basis; i.e. one nurse per two patients. This can vary and may be one to three or one to one, depending upon patient acuity. The RNs work twelve hour shifts, so there are two day teams and two night teams. When one team is on, the other is off. They usually work two to three days in a row. Night shift has an unusual addition to their schedule in that they work five nights in a row and get five nights off, twice per each six week period.

The nurses practice team rather than primary nursing. With a team approach, each nurse has a new assignment of patients each day. In primary nursing, each patient has a specific nurse assigned to them for the duration of their stay. Many of the patients in the PICU are very critical and difficult to care for. The nurses feel that it is often too physically, psychologically, and emotionally exhausting to care for the same patients every day. They prefer to work as a team while rotating the patient assignments as necessary to allow each nurse a chance to admit new patients.

Outside the PICU there is a long hallway with physician offices, the PICU Head Nurses's office, the nurses' lounge, storage rooms, a linen room, a consultation room, and a physicians' call room. There is a parent waiting room at the end of the hall. It is furnished with chairs, tables with lamps, a television set, and a telephone which can be used to place calls outside the hospital or into the PICU. There are phone booths across the hall from the parent lounge which allow more privacy. The bathrooms are located around the corner. The elevators and stairs are right outside the parent waiting room. Smoking is not permitted in the hallway or inside the lounge. Since the room is small, the parents are asked to limit the number of people in the lounge to two per patient. It is up to the PICU

nurses to inform the parents of the rules and to see that they are followed.

There are large metal double doors at the entrance to the PICU. The parents cannot observe their child from outside the unit. They are asked to knock when they arrive at the doors. During the course of this study, the visitation rules were changed. Parental visitation in the PICU had always been somewhat liberal, individualized, and only restricted during nursing report, physician rounds, certain treatments, and emergencies. Each child was allowed visitation by their parents, grandparents, and clergy. The unit became busier than in the past; patients were experiencing more complex treatments, procedures, and surgical interventions in the PICU every day. All of these happenings warranted a change.

Previously the parents had set up a pattern of gaining entrance to the PICU. They would stand in the hallway, outside the parent lounge, continuously watching the PICU entrance. One at a time, they would send one of the parents or grandparents to knock on the unit doors and ask to visit their child. If one person made it, then another parent or grandparent would go through the same procedure. They would continue this ritual throughout the day and night, so there was a steady stream of people knocking on the PICU door. The parents would usually stay up all night and watch the

unit door to see if they could get in. They often said they felt it was their duty to stay. Visitation at night followed the same rules as during the day. The nurses had to answer the door and make a decision whether the visitors would be allowed into the unit. These constant interruptions began to affect the quality and amount of care the patients were receiving. Nurses were often in the middle of starting intravenous lines, preparing life saving medications, changing dressings, or inserting urinary catheters when they would have to stop because someone was banging at the door.

In order to gain some control of a situation that was affecting patient care, a schedule was developed. This visitation schedule was intended to provide guidelines for parents to follow. It was made with the intention of allowing some flexibility while setting some limitations. A copy of the PICU visitation schedule can be found in Appendix A. This visitation change could not be postponed because the needs of the patients and the unit operation were paramount.

SUBJECTS

Selection of the subjects was made by a convenience sample of the parents of ten patients who were admitted to

the PICU for the first time and then discharged to the General Pediatric Floor. Parents who had previously had a child in a PICU were excluded. Prior PICU experience could influence the ways parents respond to concerns or create an attitude that may have inhibited their interaction at the time.

An attempt was made to obtain ten consecutive patients that were discharged. However, it became impossible due to the conflicting professional responsibilities of the research assistant and the difficulty in locating some of the parents.

Only one parent per selected patient was interviewed in order to prevent duplication of answers. There are approximately forty patients discharged from the PICU to the General Pediatric Floor per month. The sample size of ten was chosen due to the desire to conduct the interviews over approximately one week. That time frame changed, however, and the interviews were conducted over approximately four weeks.

According to Burns and Grove (1987), a small sample size is beneficial in a qualitative study in which there is a thorough examination and description of a situation. The parents were included in the study if their child met the first time admission criterion and was then discharged to the Pediatric Floor. The study continued until ten subjects

were interviewed. None of the subjects approached for this study refused to participate. All of the parents signed the consent form before the interviews began.

INSTRUMENT

The parents were interviewed by the research assistant using a list of ten open-ended questions and a demographic questionnaire in order to identify their concerns when their child was in a PICU. Open-ended questions were used to allow the subject to answer questions without preset choices. Even though the questionnaire has a checklist, it was used exclusively to facilitate the research assistant's recording. Only the actual question was read to the parent.

The appropriateness of the interview protocol for this study was assessed by having the questions reviewed and suggestions made by the thesis committee, a cultural anthropologist, and PICU nurses. A copy of the interview questions and the demographic questionnaire may be found in Appendix B and C respectively. A consent form was read and signed by each parent, indicating their willingness to participate in the study. They were given a copy of the signed consent form. An example of the consent form can be found in Appendix D. The demographic data sheets and the consent forms were not attached to the interview questionnaires so confidentiality could be maintained.

The questions were pilot tested on four parents. They did not seem to understand the meaning of some of the questions, so changes were made in the wording with the approval of the thesis committee chairman. The questions were again pilot tested with much improved results. The parents did not seem to have difficulty in determining what was being asked.

DATA COLLECTION

The parents selected for inclusion in the study were interviewed by a research assistant, a registered nurse with eleven years of experience, on the General Pediatric Floor after transfer from the PICU. Before beginning the interviews, the research assistant carefully read the research proposal and became familiar with all aspects of the method and procedure section. The research assistant went over all the plans and methods used to approach the parents, explain the purpose of the research, obtain informed consent, and conduct the interviews.

The subjects were located on the General Pediatric Floor by the research assistant. He introduced himself and followed the interview protocol located in Appendix E. He informed the parents that he was involved in determining what concerns parents of children in the PICU have had. The

purpose was identified as a collection of information to assist in improving the overall care of the child and the family while in the PICU. The parents were told that their participation may help other parents and their children who are admitted to the PICU in the future, and that honesty in answering was necessary. They were informed that the study involved answering ten questions and a demographic questionnaire. No names of either patients, parents, or nurses were recorded so that confidentiality could be maintained.

The following interview rules were adapted from Taylor and Bogdan (1984) and were adhered to by the research assistant:

1. The interview will take place in a comfortable, private setting where the parent and the research assistant can be seated.

2. The research assistant should act relaxed and unhurried.

3. The questions should be asked in a conversational manner and close attention must be paid to all answers.

4. The research assistant will take notes during the interview.

5. The research assistant must maintain a nonjudgmental attitude and not make negative comments about the parents statements or feelings. If the parents appear

fearful of being judged, the researcher may state: "I know that must be hard for you," "I know what you are saying," or "I've thought of that myself."

6. If the parent says, "I don't know what you mean by concerns," the research assistant should say, "By concerns, I mean whatever caused you problems or worries."

7. If the parent gets off the subject, the research assistant may say, "I'd like to know what concerned you most while your child was in the PICU" and then move on to other questions.

8. If the parent is unclear or vague, the research assistant should attempt to get clarification by asking for examples or for further explanation.

9. If the interview is interrupted, the research assistant will make an appointment with the parent to complete the interview.

10. When all of the questions have been asked and the interview is complete, the research assistant will ask the parent if there is anything else he or she would like to discuss. The research assistant will thank the parent for taking the time to participate in the study.

After the subjects agreed to participate, the research assistant read the consent form to them and it was signed. The parents were given a copy of the signed consent form. The ten interview questions were then read to the subject,

one at a time, while allowing adequate time for answers. Notes were taken during the interview, using the checklist and the blank spaces for quotes on the questionnaire form. After the interview was completed, the subjects were asked to answer the demographic questionnaire. The research assistant thanked each participant and then went to an office to fill in gaps in the notes. All of the information was then given to the researcher for data analysis.

LIMITATIONS

This study may have some methodological limitations which limit generalizability due to the inclusion of only one institution in the sample. If more than one PICU had been studied, the findings would have had more generalizability.

There may be other limitations due to the assumption that the subjects were reporting their true feelings and concerns. These parents may not have wanted to share painful feelings or to re-live uncomfortable events. The visiting rules changed during the course of this study and may have influenced a change in the parent's responses to the questions. A final limitation is that all respondents were Caucasian and all except one were mothers. It is possible that different results would have been obtained from a more diverse sample.

CHAPTER V

RESULTS

INTRODUCTION

Having a child admitted to a PICU is a very stressful event for parents. There are numerous uncertainties surrounding the child's hospitalization. The parents are overwhelmed by the suddenness of the child's illness or injury and the possibility that the child may die. They must interact with an array of unfamiliar people in a somewhat foreign environment. Their personal lives are placed in turmoil when family, home, work, and financial disruptions occur. Stressors cause the parents to have many concerns. These concerns can range from everyday worries to the fear that the child may die. The parents who participated in this research study expressed a variety of concerns, many similar in nature and some quite unique. This is not surprising due to the small sample size and the use of open-ended questions instead of a questionnaire in gathering data. The parent's life circumstances and personal perceptions of the situation could have influenced their answers. All responses were considered important, even if mentioned only once.

This chapter will describe the results obtained from the parents' verbal responses to the questions about what concerned them. These responses were placed into categories and themes were identified. The major themes of parental concerns included; the parent's own emotional responses, conflicting responsibilities, technical interventions, the need for information, personal concerns, and the methods used to respond to concerns.

DATA ANALYSIS PROCEDURES

Data analysis was performed following a qualitative approach. Content analysis was done on the written responses to each question in order to identify categories and themes.

The written responses to the interview questions were cut into pieces, between each question and answer. Each of the ten answers to the first question were pasted onto a large sheet of paper, each of the ten answers to the second question were pasted onto a large sheet of paper, and so on until all ten questions were sorted onto ten separate sheets of paper. Each question was then examined for recurring ideas. These ideas were categorized and highlighted with different colored pens. From these different categories, themes were identified and analyzed for frequency, importance, and meaning.

DEMOGRAPHICS

The subjects in this study included nine mothers and one father. They were all Caucasian and married. The parents ranged in age from 17 to 40 years with a mean of 28.6 years. Their highest education was reported as eighth grade for one, tenth grade for two, eleventh grade for one, twelfth grade for four, and college for two. One of the parents was employed as an office manager, one as a board of education member, six were homemakers, and two were unemployed.

The children of the parents in this study included six males and four females. Two of the children were less than one month of age, three were less than one year of age, and five were between fourteen months and fifteen years of age.

Of the ten admissions to the PICU, five had a diagnosis of multiple trauma. Three of these children were injured in motor vehicle accidents, one from a fall, and one from an overdose of medicine. Two of the children whose parents participated in this study were admitted to the PICU after surgery. The surgeries involved the repair of a heart defect and the placement of a colostomy. One child was admitted to the PICU due to a lack of bed space on the General Pediatric Floor. One parent reported that their child was admitted due to an apneic episode.

The last child was admitted due to dehydration from an ear infection and a stomach virus. The length of time these children stayed in the PICU ranged from 12 hours to 23 days, with a mean of 5.6 days. The number of other children in each family ranged from zero to three with a mean of 1.4.

FINDINGS

Emotional Responses

The parents in this study expressed a variety of emotional responses to their child's admission to a PICU. These emotional responses included; anxiety, fear, trust, guilt, shock, anger, happiness, and hopefulness.

Anxiety was discussed in a variety of ways by seven of the parents. They said they felt, "anxious," "worried," "upset and nervous," "concerned about his (the child's) small size and surgery," and "hysterical with results. I'd cry about everything the first forty-eight hours. The nurses kept us well informed." Another parent stated that they worried, "how he did at night when I was away. He's a mamma's boy."

When the parents were asked what they did when they were anxious or upset, two of them reported that talking to family and friends is what helped, two said that they cried, and one reported praying helped. Two parents said they

either paced or stood outside the PICU when they were upset. Two said that they just dealt with everything themselves and maintained control. One said they just slowed down while another identified reading as helpful.

The parents were asked who they talked to when something upset or bothered them. Eight different categories of people were named by the parents. Six of the parents said they talked to their spouse, five mentioned their child's nurse, five said a chaplain or pastor, four discussed their parents or other family members, three talked to the social worker, two to their friends, two to the other parents in PICU, one to the child's physician, and one reported not talking to anyone or seeking any help. A parent said, "Probably a chaplain should automatically come to talk with families. No one sought us out."

A parent expressed feelings of anxiety about not being allowed in the unit. She said, "If they had not put us off so many times that morning. They told us to come back in fifteen minutes, thirty minutes, then one hour; because he's sleeping. This went on for four hours or more. We wouldn't have woke him; we just wanted to see him." Another parent said she was, "Bothered by the orientation procedure of telling (her child) about the wreck. No one told me that would be done."

Feelings of anxiety and distress regarding the nurses' responsibility of enforcing the parent waiting room rules

was discussed by two parents. One parent said, "They came to read the rules (a nurse and a security guard). It intimidated us and we had to leave the floor with our parents. This was the first day after surgery." Another parent stated, "I can't get the rules straight on the waiting room. They intimidated my family with a security guard. Need kind, but consistent rules. Someone besides a nurse should monitor the waiting room."

The parents gave statements concerning fear on four occasions. They said they felt, "scared," "fearful of the diagnosis," and "Scared; I didn't know what was going on. I wasn't seeing him (the child). The nurse tried to reassure me, I was just scared."

One mother expressed fear concerning finding a blood stained blanket inside a pillow case after being transferred to the Pediatric Floor. She believed that it came from the PICU, where it was used as a back roll. The mother's greatest fear was that it was blood from another child. She was afraid that her child may have been exposed to AIDS.

Seven of the parents in this study identified that they were afraid their child would die and/or have lasting defects. Some of them mentioned both concerns. Three parents still had concerns about their child's condition. One mother even became very tearful and fearful when discussing her child's continual fever of unknown origin.

Feelings of security or trust were reported by four parents. They explained that they, "felt that she was in the best hands," "felt better after the nurses explained everything to me," "felt more secure with him being in (PICU). (I have a) firm belief in God. I trusted.", and that the nurses and doctors "were real good at understanding how we felt." One parent reported that they prayed when upset. Another reported that they just slowed down and trusted.

All of the parents exhibited trust in their child's care providers. Four of the parents reported that the quality of nursing care their child received was good while six said that it was excellent. Descriptions varied from, "good, I guess," "real good," "full attention, I'm proud of the care he got," "most of it excellent," to "very excellent." One of the parents said, "His doctors have been great too. They followed him carefully, even after he got out of the unit. This is the best hospital for children. I've talked to other parents who have had their children in all the other places around town. Everyone says the same thing. Care here is a cut above the rest." No one involved in the study said they were displeased with their child's overall care.

Other feelings expressed by the parents included, "guilty a little," "Guilty, I was driving the car.",

"shocked," "angry because she was back there (in PICU)." "happy when she did well," "hopeful," and "torn between two children, one in PICU and one on Four East (the Pediatric Floor)." One parent was somewhat upset about the nurses accidentally pulling out a cerebrospinal shunt when repositioning the child. Another was angry about the explanations given to her child. She said, "Don't talk about the condition of the patient over them. For example, 'We can't do your surgery now. You are too critical.' Give less specific information to the child. She was just fifteen years old."

Conflicting Responsibilities

Parents of children in the PICU reported feeling conflicting responsibilities while their child was in the unit. They are often separated from their other children and family members when they spend all of their time at the hospital with their ill child. Five of the parents in this study expressed family concerns while their child was in the PICU. One parent had problems deciding which of her two children she should be with at any given time, because one child was in the PICU and the other was on the Pediatric Floor. Another parent had two children in the PICU for one night. One child was discharged the next day and the other stayed for an extended period of time. All of the parents

who mentioned family concerns discussed the arrangements they had made for their other children while they were away. One family had children admitted to hospitals in two different cities after an automobile accident that injured the entire family.

Technical Interventions

Technical interventions were identified as the next theme. When asked, "What happened to your child in the PICU?" all of the parents focused upon technical interventions. One parent involved in this study said, "The equipment was overwhelming." Nine of the parents mentioned intravenous lines, seven said tubes were placed, seven said monitors were used, and four discussed oxygen or ventilators. A few of the parents were able to discuss the exact use of the tubes and monitors and identified them by name. There appeared to be a good understanding of their child's treatments.

Need for Information

The need for information was another theme that emerged from the data. The PICU environment is a great source of stress for the parents. It can be very frightening to see the PICU environment for the first time, especially if one is not prepared for the sights and sounds. A parent

commented, "It would be helpful to know what all the equipment was for. No one told me. I didn't know what things were for. You need even a five minute video."

Another source of stress for the parent is the severity of their child's condition when admitted to the PICU. The parents need information, but they do not always understand what they are told. For example, a parent expressed confusion about knowing, "whether he (the child) was eating; I didn't know he was being fed through an IV."

Three of the parents said they asked questions when they were concerned or confused. A parent said, "I asked questions and called PICU. They were always available to answer my questions. For the most part, during each visit the nurse reassured us and kept us informed." One of the parents offered that the parents should, "not be afraid to ask questions."

Two of the parents said that they could have used more explanations about their child's condition, the procedures, and the equipment. A parent who did not feel enough information was given in the Emergency Room (ER) said, "The ER staff did not seem to make an effort to explain things. But, I walked him straight back (this parent carried the child into the exam room and refused to leave)."

Information can also come from sources other than care providers. People who are going through the same situation

can offer support. A parent involved in the study said that it is helpful, "to talk to other parents (and get) moral support by mutual support."

Two of the parents requested more orientation to the equipment and to the unit prior to admission. This is sometimes done when the admission is planned, such as before an extensive surgical procedure. One of the parents stated, "We had a tour and orientation prior to the admission. We knew what to expect and were real impressed with that." However, such orientation would not be possible in situations of trauma or disease of acute onset.

Personal Concerns

Eight of the ten parents in this study discussed personal concerns they had while their child was in the PICU. The personal concerns included present sleeping arrangements, food, needing to get things from home, and personal illness and injury. A mother was in the car accident that also injured her child and said she was bruised, sore, and in need of surgery herself. Another mother stated, "My husband and grandparents were with me. I was sick myself."

One of the parents said, "Ronald McDonald House was great. The social worker told me; it helped a lot. A lot of parents won't go. They (the children) are in good hands

in PICU. Parents need to keep up their strength for when their children come out on the floor."

Financial problems were also mentioned. Two of the families' cars were destroyed in the automobile accidents that resulted in their children being admitted to the PICU. One parent said they had no car insurance. Another parent said, "They (the surgeon's nurse) have been very helpful getting us in contact with agencies for financial and material support. Nurses are very open and helpful (the PICU nurses)."

Parents who have a child in the PICU spend a lot of time in the parent waiting room between visits with their child. Three of the parents mentioned that the parent's waiting room needs some improvements. For example one parent said, "The waiting room is too small, you need a hideaway bed, and you need a smoking area. I didn't want to leave the hospital to go to the Ronald McDonald House." Another parent said that the waiting area needed, "pillows and bedding for parents staying over. It was real crowded in the PICU waiting room. We sat in the hall next to the elevator." The third parent stated that, "You really need a larger lobby. You have pastors and family members who need to visit. We had our parents with us."

Methods Used by Parents to Respond to Concerns

Parents reported that they used various methods to respond to concerns. These methods included: (a) talking to God and relying on faith; (b) talking to others, especially health care providers and other family members; (c) physical activity; (d) crying; and (e) intellectualization.

Five of the parents reported that they relied on their faith in God when they were concerned and often talked to their chaplain or pastor. One mother said, "(I have a) firm belief in God; I trusted." The parents also reported that they talked to others when they were concerned, especially health care providers and other family members. Five said they talked to the nurse, three to the social worker, and one to the physician. Six of the parents said that talking to their spouse helped while four talked to other family members. A parent said, "My niece supported me. I could not have made it otherwise."

Physical activity was used by two of the parents in response to concerns. One parent said, "I walked around," while the other said, "(I) walked back and forth (from the unit to the parent lounge) to the lobby." Two parents reported that they cried in response to concerns about their child.

All of the parents used some form of intellectualization in responding to their concerns. When

the parents were asked, "What happened to your child in the PICU?" all focused upon the equipment, tubes, and monitors. None of them mentioned their thoughts, feelings, or emotions surrounding their child's admission and treatment.

SERENDIPITOUS FINDINGS

During the course of this study, the PICU visitation rules were changed. Before the change, visitation was allowed whenever the patient's nurse permitted it. The parents had to knock on the PICU door and ask their child's nurse if they could come in to visit. The rules regarding visitation were changed to specific set times during the day when the parents and grandparents could visit their child (see Appendix A). These changes could not be postponed until this study was completed due to the needs of the patients to get more rest and uninterrupted attention by the nurses.

The responses and reactions of the parents to the change in visitation times were just the opposite of what was expected. The parents did not respond with anger or disappointment at having a set, structured visitation schedule. In fact, they expressed appreciation, trust and some relief. Most of the parents thanked the nurses in the PICU for giving them specific guidelines concerning when it

was appropriate for them to visit and when it was not. It seemed to take the decision out of their hands and that afforded some relief. One mother who was not involved in this study said, "I absolutely love these visitation times. Now I can plan my day instead of standing outside the door wondering when I should knock to go in." Another mother not involved in this study said, "It's not only good for me, it's good for my son. He knows exactly when I'll be here with him and when I'll go to eat or sleep. It has made both of us more relaxed."

The parents who have children in the PICU no longer sit up 24 hours a day, waiting and hoping to get into the unit. They know it is expected and appropriate to go and eat, sleep, and rest. They are allowed to take time out to care for themselves as well as the rest of their family. Before the visiting schedule change, a parent who was involved in this study stated in response to the question, "What did you do when something bothered or upset you?" "I stood at the double doors (the main entrance to the PICU) and kept knocking, I walked back and forth to the lobby, and I stayed up all night." Another parent involved in the study that was present before and after the visitation change commented that, "Visiting was inconsistently enforced at first, then they set up a schedule which was better." A parent involved in this study after the visitation schedule started exclaimed, "The visiting hours are real good."

Giving the parents specific, set visiting times improved the satisfaction of the parents and the children in the PICU. It allowed the parents and their child more time to rest, more security in knowing when they would see each other next, and less inconsistency in the amount of time for visits. This was a very valuable and unexpected finding of this study.

CHAPTER VI

CONCLUSIONS AND IMPLICATIONS

CONCLUSIONS

This study contributes to our knowledge by providing insight into the concerns of parents of children in a PICU. It was concluded that parents: (a) have many emotional responses to the admission of their child to a PICU, (b) report concerns about their conflicting responsibilities to other family members, (c) tend to focus upon the technical interventions used on their child, (d) need information about all aspects of their child's care, (e) have personal concerns, and (f) use different methods to respond to concerns.

Emotional Responses

The parents in this study expressed a variety of feelings at different times during their child's stay in the PICU. These included feelings of anxiety, fear, trust, guilt, shock, anger, happiness when the child improved, and hopefulness that the child would recover. Having a child in a PICU is a very difficult experience for parents. They probably felt more emotions than they were willing to

discuss in this study. Some of the feelings were probably too painful to describe and re-live. The parents go through many stages of emotions and feelings; however, each person is unique. Their life circumstances and past experiences influence how they think and feel when their child is in the PICU.

The parents were very uncomfortable with the nurses being responsible for enforcing the parent waiting room rules. The parents stated that they knew the waiting rules had a purpose and were important. However, they asked that the rules be kind and consistent. They also understood that someone must make sure that the rules are followed, but they would prefer anyone except the nurse to be in charge. The parents did not want the nurses "mad at them" for any reason. They see the nurses as their friends, helpers, and protectors, not disciplinarians. It distresses and intimidates the parents to have the nurses angry with them. They fear retaliation by the nurse caring for their child.

The parents in this study were very pleased with their child's nursing care and saw the nurse as the person who helped and comforted them. The parents reported feeling security and trust with the nursing staff.

Conflicting Responsibilities

Parents of children in the PICU experience many family concerns. They most often worry about the care and well-being of their other children who are not in the hospital. Sometimes, more than one child in a family will be admitted to the PICU. Two of the parents in this study had more than one child in the hospital at a time. They expressed confusion about deciding which child to be with at any given time. It is difficult for the parents to divide their time between their children, especially if they are in different units (one may be in PICU and one on the Pediatric Floor). The parents may feel guilty because they cannot be with both of their children at once. They must leave one child to be with the other.

Technical Interventions

All of the parents in this study focused upon the technical interventions used on their child in the PICU. The parents appeared to understand the explanations concerning the equipment, tubes, and monitors used on their child.

Need for Information

There is a great need for information, as expressed by the parents of children in the PICU. This information must

to be ongoing and adjusted to the parent's level of understanding. At times the parents may not understand the physicians' and nurses' explanations about their child's condition. They often experience shock when they first learn about their child's serious condition. The parents are confused about the cause of their child's illness or injury, the treatment administered, and the expected outcome. The fact that none of these things are predictable can compound the parent's stress. Parental injuries or illness can also prevent them from grasping the reality of the situation.

Parents are often distressed by the equipment which surrounds their child in the PICU. The equipment is mentioned frequently by parents as a source of stress. They have expressed a desire to know more about the equipment. Most of the time they want to know the function or importance of certain monitors or machines.

Parents often ask a lot of questions. Frequently they ask the same questions over and over. They are often too stressed to retain information and must ask the question more than once in order to remember the answer.

Personal Concerns

Personal concerns were addressed by the parents in this study in a variety of ways. The parents expressed a desire

to have a larger waiting room so that other family members, friends, and ministers could visit with them. They need a quiet, comfortable place where they can relax, read, and talk between visits with their child. They need the support and presence of their family members, friends, and clergy. They need their loved ones close by in order to share their experiences and feelings.

Parents of children in the PICU, who were involved in this study, expressed a desire to have a designated smoking area. They feel that going to the first floor is too far out of the way. In 1990, all of the city hospitals plan to restrict smoking inside the buildings. Visitors will be required to go outside to smoke. It is difficult, if not impossible, to expect the parents to stop smoking when they are in a hospital. They are extremely anxious and stressed and probably smoke more than they normally would.

Sleeping arrangements are a concern of all parents who have a child in a PICU. They feel obligated to stay at the hospital in case something were to happen to their child. They are often afraid that the child may need them and they want to be close by. When the PICU visiting rules were unrestricted, all of the parents slept in the parent waiting room and refused to go anywhere else at night. There are no cots or couches in the waiting room and the chairs are not very comfortable. The parents who slept in the PICU waiting

area night after night become absolutely exhausted within a few days from worry and lack of sleep. Some of the parents in this study discussed the importance of getting sleep. They expressed their appreciation at having the Ronald McDonald House to go to when they were tired.

When the child is transferred to the General Pediatric Floor, a parent must stay with them. It is much more physically demanding to care for the child on the Pediatric Floor than most people imagine. The child is still very ill and requires a lot of attention. They may also be very demanding and irritable. The parents who manage to get at least a minimal amount of sleep while their child is in the PICU seem to fare better when their child is moved to the Pediatric Floor. As one parent stated, "They (the parents) need their strength for when their children come out on the floor."

Methods Used by Parents to Respond to Concerns

When the parents of children in the PICU wanted to talk to someone about their concerns, they most often chose their spouse, the nurse, or a chaplain. These people seem to be the most trusted by the parents and offer the most comfort to them. Also mentioned were their own parents or other family members, the social worker, their friends, other parents of children in the PICU, and their physician. One parent did not seek anyone to talk to during their stay.

Serendipitous Findings

During the course of this study, the PICU visiting rules were changed to set, regulated times when the parents are allowed to visit their child. The only time when the parents are allowed to sleep in the lounge is when their child is first admitted to the PICU. The parents can sleep in the parent lounge on the first night of admission or if their child becomes extremely unstable. No one can visit the children in the PICU after 10:30 pm. The children and the visitors are encouraged to sleep at night. The parents are asked to make arrangements to go home, to the hospital motel, to the Ronald McDonald House, to a relative or friend's home, or to a motel of their choice.

The nursing staff have observed that the change to a regulated, set visitation schedule has resulted in calmer, happier, and more rested parents. None of the parents have complained about the visitation schedule; in fact, most of them have expressed their pleasure at having guidelines. The new rules seems to give their day structure. When parents have a child in a PICU, they are often very vulnerable. They concentrate on the child's condition and may not be able to expend the energy it takes to make decisions they consider unimportant, such as when to eat and where to sleep. Their child's condition occupies their thoughts. All of the parents seem relieved to have the

staff's permission to eat, sleep, and rest. They are given some free time during the day and night to take care of themselves and the other members of their family. This is in direct conflict with the studies done by Proctor (1987) and Stillwell (1984). Proctor concluded that mothers were less anxious if visitation was individualized while Stillwell concluded that families want visitation to be unrestricted and flexible.

IMPLICATIONS

Several clinical implications can be drawn from this study. PICU nurses in practice should: (a) provide care and support to the parents as well as the child, (b) listen to the parents feelings and concerns, and (c) serve as a parent advocate. In addition, the nurses should consider: (a) organizing and facilitating parent support groups, (b) implementing a structured, well-defined PICU visitation schedule, (c) making a parent orientation video available, and (d) putting volunteers or secretaries in charge of the parent waiting room.

Most admissions to the PICU are unplanned. They occur as a result of a child's sudden illness or injury. The parents do not have time to prepare for the ordeal mentally, physically, or emotionally. There is uncertainty about the

child's condition and the possibility that the child may die. Once the child's condition stabilizes, there is the concern that the child may suffer long term disabilities or lasting defects.

Parents are the most important people in a child's world. When a child is seriously ill or injured, the child especially needs their parent's physical and emotional support. The child is well cared for in the PICU; however, the parents do not get enough attention. They must be considered in all aspects of the child's care in order for it to truly be successful. The parents' concerns have long been ignored. However, they must be examined and addressed in order to treat the whole child.

According to Neuman (1982), there is an effect upon the whole system when something affects a part or a subpart of the whole. The child who enters the PICU is a part of a whole family system. In order to treat the child, the entire family must be given consideration.

Physicians and nurses must listen to the parents in order to determine their feeling and concerns. Nurses are in the best position to talk to the parents about their feelings and concerns. Nurses must try to assist the parents in expressing their feelings and emotions without being judgmental. If the parents do not express their concerns and feelings, the nurse should approach the

subject. The nurse may not be able to give the parents answers or solutions to all of their problems; however, he/she can offer to listen and reinforce that they are not alone or crazy. Many of their emotions, feelings, and concerns seem frightening and strange to the parents. The nurse can help the parents to express their concerns and offer information and guidance in decision making.

The sight of a child who is seriously ill is often frightening to the parents. The child may have sustained broken bones, the loss of a limb, swelling of the face, severe bruising, or bleeding. These injuries can drastically alter the child's appearance. If the child is also comatose, the parents may be even more distressed. Preparation of the parents, prior to entering the PICU, is very important. They need to be told what they can expect to see before they actually see it. The nurse needs to reinforce what is happening to the child in terms that the parents can understand. They need to know exactly what is wrong with their child and what the treatment plan will be. However, the details should not be discussed in front of the child. It is appropriate for the child to know where they are, why they are in the PICU, and what is going to happen; however, they do not necessarily need to know the graphic details.

Nurses and physicians should repeat their explanations at intervals throughout the child's hospital stay. The

parent's level of understanding could be assessed by having them repeat what has been explained to them or by having them describe the situation in their own words. Misconceptions could be cleared up at that time and additional information could be given. Nurses should explain the different pieces of equipment to the parents; however, this needs to be done more than once in order to be successful. One of the parents in the study expressed a desire to have even a five minute video available. This would be an excellent idea for the parents who have a child admitted to the PICU. It could be played whenever the family felt they were ready to take in the information. It could be played over and over or at different periods during the hospitalization. It would also be helpful to have one of the more articulate and experienced parents on the video explaining some of the PICU equipment and visiting rules in terms that the parents could understand. Their insight into the worries and concerns felt by the parents would be a very valuable addition to the orientation video.

Nurses in practice must be patient with the numerous parent questions. This must be treated as a normal response to stress. When the situation is less tense, the parents will be able to comprehend and retain new information.

Nurses should serve as a parent advocate. For example, in instances when siblings are hospitalized, nurses should

try to keep them together. The siblings can share the same room on the General Pediatric Floor in order to assist the parents in caring for both children without feeling that one or the other is being left out. This advocacy role may require considerable assertiveness and planning on the part of the nurse.

Nurses should also serve as parent advocates to improve the parent waiting room space. The parents need a larger waiting room that can seat at least six people per patient. The parents need their family, friends, and clergy close by for support. Nurses must be vocal in making this need known to the hospital architects, administrators, and planning department.

As mentioned by a parent in this study, the parents would benefit from talking to other parents who have had a child in a PICU. They need support from others who have been in the same, or similar, situation. Support groups for parents of children who are seriously ill or injured should be formed and facilitated by PICU nurses. Group discussions by peers in the same situation would help the parents to express their feelings while offering them feedback and new ideas from others.

The results of this study imply that parents want structured, well defined visiting times that follow a routine schedule. This is in contrast to all of the studies that have addressed intensive care visitation.

When a child is seriously ill, the parents often become very anxious, fearful, confused, and weak. Their energy is rapidly depleted. They need to sleep at night, to eat regular meals, and to relax at intervals throughout the day in order to maintain their energy and health. They need to retain their strength in order to care for their child's physical and emotional needs. The child in the PICU needs the support of their parents in order to get well. Parents will literally wear themselves out if they are not given a structured schedule that includes times for resting, eating, and sleeping. Structured visiting times gives the parents a way to plan their day during the most uncertain and confusing time of their lives.

Some form of physical exercise could be beneficial to the parents in the PICU. The exercise could be used as a stress management technique. Exercise times could be structured or unstructured. Volunteers could be available to lead the interested parents in periodic stretching exercises. The parents could also be encouraged to take long walks outside between visits with their child.

Nurses should not be the ones to discipline the parents actions in the parent lounge. Security personnel, volunteers, or lounge secretaries should monitor the parents behavior in the lounges. Nurses must retain their role as kind helper and trusted friend of the patients and their families.

FUTURE RESEARCH

The concerns of parents who have a child in a PICU need to be addressed further. Qualitative, descriptive studies should be done in other PICUs and the results compared with this study. The concerns of mothers and fathers should be studied separately. In this way, gender differences and social role expectations that may influence their concerns could be examined.

A study should be done in several PICUs to determine if structured or unstructured visitation is beneficial to the parent and the child in a PICU. The effects upon the parents, the child, and the nurses of changing from unstructured to structured visitation could be studied in a controlled setting in future research.

SUMMARY

The concerns of parents must be taken into account when planning care of the child in a PICU. Parents help their children to get well. The parents are often stressed by the child's serious illness and need support, comfort, and information from the physicians and nurses. Parents feelings and concerns vary according to their life circumstances and level of understanding of the situation.

They consistently request information about the PICU environment and the child's medical condition. They need structured visiting times which allow them time to sleep, to eat, and to attend to their other children and personal concerns.

Parents want the nurses to retain their roles as kind helpers and trusted friends. They do not want the nurses to ever be placed in a situation where they may get angry at them. Each of the PICU patients and their parents are unique individuals who need the support and care of the nursing staff. Parents concerns must be considered and addressed. In order to successfully treat the child, the whole family must be treated.

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APPENDICES

APPENDIX A

VISITING YOUR CHILD IN THE PICU

The Pediatric Intensive Care Unit (PICU) is a special place where doctors and nurses take care of children with life-threatening illnesses and injuries. Monitors, tubes, medicines, and treatments are used to help the children get well.

Children in the PICU need their parents to help them feel better. However, having too many people around can actually cause problems for the child. This is not a time for friends and other family to visit. The children are weak and need more rest than usual.

In order to give your child the best possible care and to give you an idea how to plan your day, the following times can be used for visitation by the parents and grandparents.

8:00 am	-	8:30 am
11:00 am	-	12:00 noon
2:00 pm	-	3:00 pm
4:30 pm	-	5:30 pm
8:00 pm	-	9:00 pm
10:00 pm	-	10:30 pm

These times may change if a new patient comes in or if the doctors and nurses need to give a child a special test or treatment.

APPENDIX B

Interview Questions

1. What is your relation to the child?

Father _____
Mother _____
Grandparent _____
Guardian _____
Other _____

2. Why was your child admitted to the PICU?

Medical condition:

Cardiopulmonary arrest _____
Respiratory illness _____
Sepsis _____
Seizures _____
Congenital defects _____
Other _____

Surgical condition:

Trauma _____
Post-op _____
Other _____

3. What happened to your child in the PICU?

Was there for observation _____
Was in for life saving treatments _____
Was in for care by nurses and doctors _____
Care was good/excellent _____
Care was not good _____

4. Many of the parents we've talked to say they have a lot of different feelings, from the time they learn their child will be in the PICU, until discharge. Please, think back through this time and see if you can tell me how you felt.

Shocked _____
Disbelieving _____
Helpless _____
Guilty _____
Lonely _____
Anxious _____
Angry _____
Relieved _____
Mournful _____
Happy _____
Other _____

5. What were your concerns while your child was in the PICU?

That the child would die _____
That the child would have lasting defects or problems _____

Personal concerns:

Sleep _____
Food _____
Support _____
Other _____

Family concerns:

Spouse _____
Other children _____
Other _____

(Can you think of others, even some of the small concerns or worries?)

6. What did you do when something bothered or upset you?

7. Did you talk to someone when something upset or bothered you?

or

Is there anyone else you talked to when something bothered you?

Spouse _____
Parents _____
Chaplain _____
Friend _____
Nurse _____
Physician _____
Other _____

8. Can you think of anything, no matter how small, that the nurses could have done to have helped you more?

9. From what you have observed and heard, as well as what you have been through, tell me what else would be helpful to the parents whose children are in PICU?

10. Is there anything else you would like to add?

Date and place of interview:

Note any unusual events that occur during the interview:

APPENDIX C

Demographic Data

Subjects:

Marital status_____

Age_____

Race_____

Highest education_____

Employment_____

Child's:

Sex_____

Age_____

Length of stay in the PICU_____

Number of children in the family_____

APPENDIX D

Consent Form

A nursing research study is being conducted in order to determine what concerns the parents of children in the PICU have had. The purpose of this collection of information is to improve the overall care of the children and their families while they are in the PICU.

The study involves answering ten questions about your experience and feelings while your child was in the PICU and will take approximately 15 to 30 minutes. No names will be recorded on the answers to the questions or in reporting the findings.

Participation in this study is voluntary and refusal will not result in penalty. Answering the questions implies willingness to participate. You have the right to withdraw at any time. If you have any questions about the study, you can call Ms. Ford at 544-9840.

Date

Subject's signature

Witness

APPENDIX E

Interview Protocol

Introduction

Hello, my name is Ben Francisco. I am involved in a nursing research project to determine what concerns the parents of children in the PICU have had. The purpose of the project is to improve the overall care of children and their families while they are in the PICU.

The study involves answering ten questions about your experience and feelings while your child was in the PICU and will take approximately 15 to 30 minutes. Honesty in answering is necessary. No names of either the patients, parents, nurses, or doctors will be used when I write down your responses. No tape recordings will be made.

After talking with ten parents who have had children in the PICU, the answers will be compiled to see the number of similar concerns. Hopefully, the results of this project may help other families who have children in the PICU in the future.

Do you agree to participate?

Possible Questions

Question: Can my family and I answer the questions together?

Answer: Because of the difficulty in interviewing too many people at once and the need to keep the total project to ten parents, I can only interview one parent per family.

Question: What if I do not want to answer some of the questions?

Answer: You can decline to answer any or all of the questions. Your participation is completely voluntary and very much appreciated.

Question: Will the nurses or the doctors be told what I tell you?

Answer: I will not use your name when I write down your responses.

VITA

Donna Kim Ford was born in Blytheville, Arkansas on March 10, 1956. She attended school in Knoxville, Tennessee and graduated from Central High School in June 1974. The following September, she entered the University of Tennessee, Knoxville. She received a Bachelor of Science degree in Nursing in June 1979. The following month, she accepted a position as a staff nurse in the Pediatric Intensive Care Unit at the University of Tennessee Medical Center. In 1983, she became the Assistant Head Nurse and in 1986, she became the Head Nurse. In the fall of 1986, she began study towards a Master's degree in Nursing. This degree was awarded in May 1989.

The author is certified by the American Nurses' Association as a Child and Adolescent Nurse (RN, C) and by the American Association of Critical Care Registered Nurses as a Critical Care Registered Nurse (CCRN). She is a Pediatric Life Support Instructor and a Pediatric Advanced Life Support Instructor. The author is a member of the American Nurses' Association and the American Association of Critical Care Nurses. Ms. Ford will continue employment with the University of Tennessee Medical Center after graduation.